

Leukaemia Today

Supporting people *living* with leukaemia



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Kia ora,

Welcome to your Winter 2025 edition of Leukaemia Today.

Over the past 12 months, LBC's Support Services team has stood alongside nearly 1,700 people

newly diagnosed with blood cancer, and their whānau, through one of the most challenging times in their lives. Every day, I see the care, commitment and professionalism our team brings to meeting the unique needs of patients across the country.

For some people, support means understanding their condition and knowing what to expect. For others, it means practical help, connection with others, emergency financial support or access to counselling during a difficult time. Our team takes the time to listen and then responds based on what matters most to each person. It's a personalised approach we take a lot of pride in.

As we continue to build our support capacity, LBC's goal is to connect with more patients across the country. If you or someone close to you is affected by blood cancer, please consider reaching out to our Support Services team – we're here to help.

While supporting the best possible outcomes for blood cancer patients diagnosed today, we're also ramping up our efforts to transform future outcomes. For some cancers, that means advocating for access to potentially life-saving treatments available overseas. For others, it's funding research that brings us closer to better therapies and, ultimately, cures. And in many cases, it's both at the same time.

Inside this edition, you'll find updates on our progress and stories from across the leukaemia community. Whether you're newly diagnosed, in treatment, or supporting someone who is, we hope these pages offer encouragement and reassurance.

Ngā mihi,

Tim Edmonds
LBC Chief Executive

Progress on bringing CAR T-cell therapy to New Zealand

At LBC, we're focused on making sure Kiwis can access the best global standard of treatment. One example is CAR T-cell therapy, a highly specialised treatment that has helped thousands of blood cancer patients around the globe, often leading to long-term remission or even a cure.

At the moment, Kiwis are travelling overseas to access this therapy. This can place a huge financial and emotional strain on them and their families. The exciting news is that a partnership between the Malaghan Institute and BioOra means this therapy is now being made here in Aotearoa at a much lower cost. It is currently being tested in a clinical trial called ENABLE-2, which is open to people with a certain type of lymphoma.

LBC is proud to support patients participating in this trial by assisting with travel and accommodation costs. As trial results emerge, we look forward to working alongside innovators and the health system to ensure that CAR T-cell therapy can be delivered here in New Zealand to the people who need it most.

State of the Nation

LBC is currently working on a State of the Nation report to capture a complete picture of the state of blood cancer care in New Zealand. The report aims to identify critical gaps, highlight areas for improvement, and detail a roadmap towards a future ambition of 'zero lives needlessly lost to blood cancer'. Central to achieving this is having a deep understanding of the real-life experiences and perspectives of patients. This is why we partnered with experts at Deloitte to develop a research approach that would capture detailed patient insights.

This comprehensive research includes surveys, focus groups, and in-depth one-on-one interviews. We received an incredible 785 responses to our patient survey, gained valuable insights through a focus group with parents of children diagnosed with blood cancer, and conducted detailed interviews with five individuals who bravely shared their personal experiences.

Many findings reinforced themes we were aware of but had not yet systematically documented or measured. Importantly, this research also revealed new insights into groups that are currently underserved and not meeting government targets for receiving timely, high-quality healthcare.

These findings clearly demonstrate the realities of blood cancer care and provide strong evidence to inform necessary policy changes. This ensures we can accurately and effectively represent patient voices when engaging with policymakers.

Thank you to everyone who has participated so far – we look forward to sharing the final report with you later in the year. For those interested in supporting future advocacy, there will be more opportunities to join us as we continue working towards meaningful, positive change for all those affected by blood cancer.

HSANZ Conference highlights

We were proud to have two presenters from LBC at this year's Haematology Society of Australia and New Zealand (HSANZ) conference, where clinicians, researchers, and advocates gathered to share progress in blood cancer care.

Tim Edmonds introduced LBC's role in advocacy and support, outlining how we work to shape the future of blood cancer care through strong partnerships and patient-focused initiatives. Rosie Shaw's presentation was on New Zealand's medicine decision-making processes. She used CAR T-cell therapy as a case study to highlight the urgent need for modernisation in access and funding pathways. Both presentations were well received, with strong engagement from attendees who appreciated the patient-centred perspective and practical insights into the challenges facing Kiwis with blood cancer.

Members of LBC's Support Services team also attended the conference to showcase our patient resources, gather insights from haematology professionals to enhance our service delivery, and strengthen connections within the sector. The conference provided a valuable platform to ensure patient voices continue to inform research, policy, and clinical planning decisions.



LBC's stand at the HSANZ Conference

Celebrate your milestones

For Evelyn Aispurua, the last five years have brought indescribable pain and heartache. She's faced a cancer diagnosis, the death of her father, long periods separated from her young daughter, and the end of her marriage.

Despite these challenges, Evelyn's positivity is unwavering. Spurred on by her own struggles, she's passionate about supporting others as they go through difficult times. *"I assist people to connect to a moment of peace within themselves,"* she says. *"I use different tools like aromatherapy, massage and sound healing to help them connect to their five senses."*

The COVID-19 pandemic was taking hold around the world and Evelyn was living in Bali with her family, helping stranded Argentinians to get home in the middle of a strict lockdown. She was extremely stressed.

"I started having these pains, these aches in my legs that were very weird, until one day I almost couldn't walk," she recalls.

She went to see her doctor and was referred to a rheumatologist, who diagnosed her with rheumatic fever. *"He gave me pills, I took them, and some of the symptoms went down – until I started haemorrhaging..."*

Evelyn returned to her GP and was referred to another specialist. *"I actually found out about my diagnosis by the GP sending me a photo of a letter to take with me to the hospital, saying 'possible leukaemia'. I was like, 'What the hell!?'"*

Further tests at the hospital confirmed she had acute myeloid leukaemia. She needed treatment urgently, but was told it would be a huge out-of-pocket expense in Bali and that treatment was much more advanced back in New Zealand.

She was urged to get home to New Zealand as soon as possible so she could begin treatment in the public health system.

Just seven days after receiving her diagnosis, she was on a plane to Auckland with her husband and five-year-old daughter. From the airport, it was straight to Auckland Hospital, where she was started on chemotherapy and kept in complete isolation for the first 15 days due to arriving from overseas. *"I had a security guard outside my door 24/7 so that they could make sure I didn't come out and compromise anyone else."*

Evelyn's treatment went on for months, and even when COVID restrictions eased, she was told her daughter was too young to visit her in the ward.

Finally, after six months, Evelyn was discharged from the hospital. Thrilled to be reunited with her husband and daughter, they packed up the car and headed off on a road trip together. She remembers this period fondly.

👂 **Then, just nine months after my first treatment, I relapsed.** 🐣

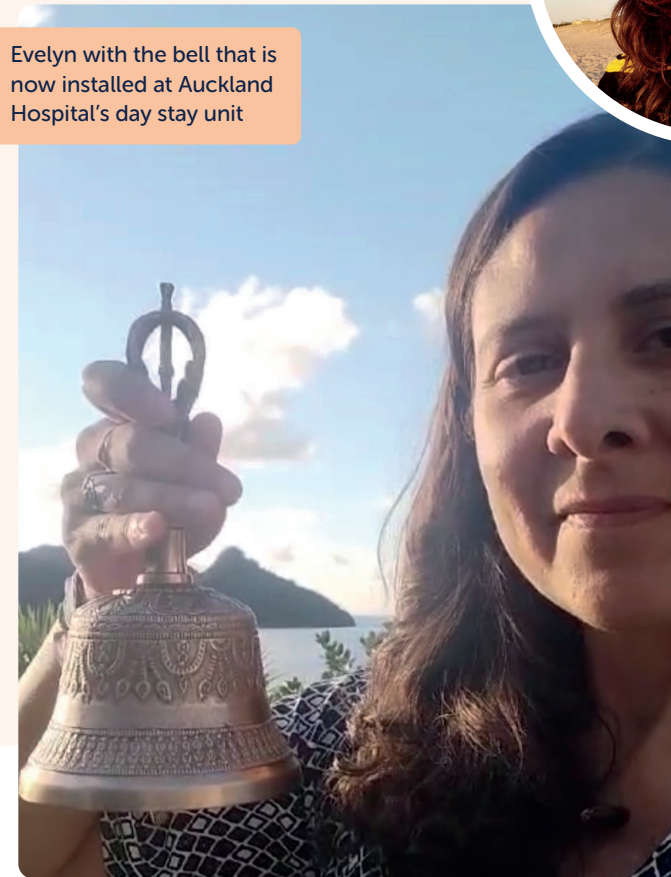
Evelyn knew she would need a stem cell transplant this time. Her doctor encouraged her to start back on treatment straight away, but she was hesitant to begin chemotherapy before having a donor lined up. It was agreed that she could stay out of the hospital for the time being, under the condition that she be closely monitored.

Having bought herself some time, she did her best to help find a suitable donor.

"I made a video, and I shared it with the Latin community. We had hundreds of people trying to give blood to see if they were a match with me."

In the end, Evelyn's mother flew over from Argentina to be her donor. Evelyn says the transplant process was tough – she was often in severe pain, and again she found herself all alone in a hospital room. *"I spent a lot of time isolated throughout all that time,"* she says. *"Again, my daughter couldn't come in. I spent New Years and my birthday inside."*

Evelyn with the bell that is now installed at Auckland Hospital's day stay unit



Evelyn used breathing techniques, meditation and colouring in special designs to help her cope. Unfortunately, the side effects didn't end once she was returned home from the hospital.

"I ended up having graft versus host disease. So for almost two years, I've been battling with that. And because the transplant erases your immune system and your vaccines, I ended up getting chicken pox."

Throughout everything, Evelyn has been blown away by the incredible support she's received both in and out of the hospital.

"Annette from LBC is amazing. Since I came back to Auckland in December, she's been calling me, reaching out, sending emails, asking how I am, how she can help."

Once Evelyn felt strong enough, she started going along to Annette's support groups, as well. *"They're all about how we can assist each other. We just go in and talk, express ourselves, and not hold anything back. It's nice to relate to people who understand."*

Throughout her journey, Evelyn has stayed focused on what she is thankful for



After spending much of her life in the hospital over the past several years, Evelyn has now done something amazing to benefit other cancer patients going through a similar journey. *"There's this thing in the US and other places where people celebrate with a bell once they finish their treatment and are in remission. I wanted to introduce that here."*

"When you're lying down in your hospital bed and you cannot move or you're just feeling miserable, hearing that someone else is celebrating – no matter what they are celebrating, maybe they've finished treatment, maybe they got their neutrophils up and they can get out of hospital – it would make me feel joyful. Because if they can do it, I can do it."

In April, Evelyn was thrilled to be given the go-ahead to install the bell at Auckland Hospital's day stay unit.

"A normal bell wasn't enough – so it's a handmade ceremony bell from Nepal. They're going to place it at the entrance, at the front desk. I'm going to put a little sign on it, saying 'Celebrate your milestones'."

Fast Facts: AML

- Abnormal white blood cells rapidly multiply in blood and bone marrow, crowding out healthy cells, leading to symptoms like fatigue, frequent infections, and easy bleeding.
- Around 130 New Zealanders are diagnosed each year, mainly older adults.
- AML progresses quickly and needs immediate treatment. There are multiple subtypes and different genetic variations.

Looking ahead

Online Patient Forum

We're pleased to announce this year's Online Patient Forum, "Healthcare Compass – Haematology Updates in 2025".

Join us online this September for four informative sessions designed to empower patients throughout their healthcare journey. These webinars will explore patient rights, treatment landscapes, navigation of care transitions, and future directions in haematology care in New Zealand. Sessions will be held weekly throughout the month, providing valuable insights and practical guidance for patients and their families.

Registration details and final topics will be announced soon – we look forward to seeing you there!



Shine for a Cure

Do you want to shine a light on blood cancer? On Saturday, 20 September, you can join Kiwis in Auckland, Christchurch, and across the country as we light our lanterns and walk together to raise money for blood cancer research.

It's completely free to register and come along. There's no pressure to fundraise, but if you'd like to, you'll receive a free lantern when you raise \$100 or more. The three lantern colours represent why you're taking part – teal symbolises a personal journey with blood cancer, gold is to remember those who are no longer with us, and white shows support for all those affected by blood cancer.



If you can't join us at Auckland Domain or Hagley Park this year, you're also welcome to hold your own lantern event wherever you are in the country and join the live stream online.

Keep your eyes peeled for more information on how to register!

Battle Bus Bonanza

We know that one of the hardest parts of a child's blood cancer journey is the feeling of isolation. That's why we created Battle Bus Bonanza, a special initiative designed to bring young patients together through the power of video game tournaments!

This isn't just about playing games – it's about building connections. Battle Bus Bonanza brings together kids, their families, healthcare teams, and fellow patients in a supportive, fun, and interactive environment. It's a chance for kids to take time out from their treatment to connect with others who truly understand, and have a blast while doing it!

We have two exciting tournaments lined up later this year, and we'd love for your child to be a part of them. If you're a parent of a child living with blood cancer and want to get involved, reach out to Tim Maifeleni at TimM@leukaemia.org.nz for more details.

Introducing our newest factsheet



We're delighted to bring you our newest educational resource, "Immunotherapy and Cancer", developed in partnership with the Malaghan Institute of Medical Research. This factsheet explains how immunotherapy works by harnessing your body's own immune system to recognise and attack cancer cells. It explores the different types of immunotherapy treatments, including monoclonal antibody drugs, immunomodulators, checkpoint inhibitors, CAR T-cell therapy, bispecific antibodies, and vaccines.

Whether used alone or in combination with treatments like chemotherapy, immunotherapy represents an important advancement in cancer care, and we're pleased to be able to share this informative resource with you.

Head to www.lbcnz.link/immunotherapy or scan the QR code to read the full factsheet.



Supporting your immune system

Want to give your immune health a boost? Here are five key things to focus on:

- Eating well
- Keeping active
- Taking care of yourself
- Getting enough sleep
- Keeping up to date with your vaccinations.

The best thing since sliced bread

This year marks 25 years since the medication imatinib (Glivec) was first used to treat chronic myeloid leukaemia (CML) in New Zealand. Carol Clarke, the first New Zealander to begin taking the game-changing treatment, tells her story.

Back in 2000, Carol and her husband Graham were living in Rotorua, where Carol worked as an insurance consultant. Their sons had left home, and the couple had taken up dancing in their free time.

"We were having a lesson one day, and I couldn't even do one round of the floor," Carol recalls. "I was just exhausted."

Carol was 52 at the time. She'd been having night sweats and hot flushes, so she assumed she was probably going through menopause.

Her GP agreed that this was the most likely explanation for her symptoms and suggested hormone replacement therapy. *"He said we'd do a blood test now, and another blood test in two months' time. And then he phoned me at 9 o'clock one Saturday night."*

Concerned with her results, the GP asked Carol if she'd had an infection recently. When she told him she hadn't, he ordered a repeat blood test for two weeks later. Not long after the second test, Carol was called back into the doctor's surgery and given the devastating news.

"My GP said he was 99% sure I had CML."

At the time, CML was treated with interferon and chemotherapy. On average, patients only survived four to five years. Carol was terrified.

“I thought it was a death sentence.”

She was referred to a haematologist, who confirmed her diagnosis, but also offered some promising news. It just so happened that in 2000, a trial for imatinib, a new drug to treat CML, was starting in New Zealand. Carol was diagnosed in April, and the trial was due to start in October.



Carol was the first Kiwi patient to take the revolutionary CML drug imatinib

To be eligible for the trial, Carol must not have tried any previous treatments. As she waited for the trial to start, her blood test results continued to worsen. *"My doctor said to me, 'Carol, your blood counts are going up. I don't think you should wait for the trial.' And I told him, 'I'm going to wait.'"*

On 22 October, 2000, Carol took her first dose of imatinib, making her the first Kiwi patient to trial the drug.

Within just six months, she was in remission.

"It was splashed all over the paper, and I thought, 'What's all this fuss about?' But it had been the biggest breakthrough in about 25 years, apparently. The best thing since sliced bread."

That's not to say it was all plain sailing.

"The side effects were pretty harsh – I had puffy eyes and my hair went very thin – but it saved my life."

Carol continued taking imatinib for 17 years. Life continued as normal – her energy returned and she kept working, only taking the odd day off for doctors' appointments.

Then one day in 2017, Carol collapsed. After being rushed to the hospital, it was discovered she was bleeding internally and needed urgent surgery. *"The doctor who did the operation said to me, 'You had absolutely nothing left.' My haemoglobin was in the 60s or 70s."*



Carol has now been off imatinib since 2017 and her blood tests have remained stable

Once she was stable, it was suggested to Carol that her medication might have been the cause of the bleeding. *"They said to me they were going to take me off it, and I got very nervous then, thinking, 'Gosh, I've been on it for so long. Is the leukaemia just going to come back rampant again?'"*

She sought a second opinion from another haematologist, who agreed that stopping treatment was the right decision.

“So I came off it, and here I am – still here!”

Carol still gets blood tests every three months to keep an eye on things, but so far, her CML has stayed under control.

Devastatingly, Carol recently lost Graham after 58 years of marriage. Adjusting to life without him has been tough, but she's got great family and friends who have rallied around her.

After living in Rotorua for 40 years, she now lives in Cambridge and enjoys going along to her local LBC support group. *"Everybody else has had the same thing or is going through some sort of treatment," she says. "They're nice ladies."*

25 years on from when she was first diagnosed, Carol is aware that things could have taken a very different path if she'd been diagnosed even just a year earlier.

"If I had to get CML, I got it at the right time."

She doesn't take the time she's been given for granted. *"I really didn't think I would last 25 years, to be quite honest. Somebody's looking after me!"*

CML affects around 70 New Zealanders every year. This year, we celebrate 25 years since the introduction of Tyrosine Kinase Inhibitors (TKIs), a breakthrough that transformed outcomes for thousands of CML patients.

Healing after treatment



Annette Cody works as a Support Services Coordinator in the Northern region. She is both a registered nurse and a counsellor, and holds a Masters of Health Science focusing on the psychological and spiritual impact of disease. Here she reflects on the process of healing after treatment ends and gives some advice on how you can support yourself through this time.

Your feelings are normal

After successfully completing treatment, we usually expect to feel better. There may be an expectation that we feel grateful. Yet some people feel depressed, anxious, lost and emotionally worse than before the diagnosis. Medical interventions can only take us so far on the road to recovery and wellbeing. We also need psychological support to process and adjust to changes.

Accept your emotions

It is important to allow our feelings. Sometimes we benefit from naming the emotion, for example anger, and acknowledge that other people in our situation might also feel angry. If we can accept the feeling, without acting it out, there may be a softening, a releasing of that feeling.

You're not alone

LBC offers a range of support groups and closed Facebook groups where you can connect with others. For more details on these and our other resources, refer to our website or contact your local coordinator.

Watch your thoughts

Notice if you have intrusive or disturbing thoughts that repeat. An example is 'the cancer will come back'. When thoughts create an emotional charge like fear, we tend to believe them. We need to be aware of these thoughts, challenge them, and counteract them. They are just thoughts.

Mourn and acknowledge your losses

We don't have a choice about feeling symptoms of grief, but we do have a choice about how we acknowledge and process our grief. Losses may include the financial cost, the loss of trust in our body, the impact on our vitality. Remember that the symptoms of grief can manifest in a variety of ways, in our bodies, thoughts and feelings. So, it is important to be kind to yourself. Cancer is an uninvited and sometimes overwhelming intrusion on our wellbeing. It can take courage to acknowledge the impacts and find new ways to engage in life.

Meet our new support services staff



Tina

Last year, we welcomed Tina Stewart as a Support Services coordinator in the Midland Region. She has previously worked as a health professional and has broad experience across the New Zealand health sector. Tina is passionate about supporting the quality of life of blood cancer patients and their whānau. Her goals for 2025 include expanding existing services where needed and improving equity across the regions she covers, including Waikato, Tauranga, Whakatane, Thames, Coromandel and Whitianga.



Melody

A familiar face to some, Melody has returned from parental leave and is working alongside Sally and Nicki in the Central Region. She has a background in nutrition and dietetics and has previously worked as an oncology and haematology dietitian in both New Zealand and the UK. Melody works part-time, looking after LBC's private Facebook groups, developing high-quality patient resources with the health literacy team, and helping the Wellington team with patient support. She is passionate about helping patients and families to feel supported and empowered in their journeys.



Vanessa

Vanessa recently joined the Support Services team as the Support Services Administrator. She has a strong administration background, having worked for one of New Zealand's largest retirement villages as well as running her own business. Vanessa works full-time in the Auckland office and assists the Support Services team nationwide. She prides herself on ensuring things run smoothly behind the scenes so that the team can focus on delivering support to patients and their families.

A day in the life at LBC

Tim, Annette and Natasha from our Auckland office recently helped make a short video about what the Support Services team get up to day-to-day. In it, they share a glimpse behind the scenes and discuss the different ways they provide support to patients and their families.

"I love my support groups. I love being part of an environment where there's space for the difficult feelings to arise and be held by everybody, and there's space for the love, and there's space for the optimism. It feels like humanity at its best." – Annette, Support Services Coordinator (Northern Region)

Head to www.lbcnz.link/dayinthelife to watch the full video.

Resources and support corner

Education and support programmes

We host support groups for patients and their whānau across the country. Groups are held both in-person and online, and they allow you to meet and connect with others facing similar challenges.

The programmes aim to help you make informed choices about your condition, treatment and lifestyle.

To find a patient support group near you, head to lbcnz.link/groups or scan the QR code.



Educational materials

We produce a wide range of patient information resources, including booklets and factsheets.

These are designed to help you understand your condition, its treatments and other topics like managing fatigue, chemo brain, eating well, and sleep – plus many more!

Head to lbcnz.link/info or scan the QR code to view our full library of information resources, or contact your local Support Services Coordinator to order printed copies.



Kids' Zone

LBC also offers a range of services and programmes for young people affected by blood cancer. We run Super Kids' Club for children living with cancer, and Kids' Club for children who are affected by a family member's diagnosis.

These groups are facilitated by play therapists and psychologists, and give children space to talk about their feelings, learn a bit about cancer and treatment, and meet other kids going through a similar experience.

We also offer picture books for kids, as well as a range of other initiatives. To find out more, go to lbcnz.link/kidszone or scan the QR code.



Facebook

You can also follow @LBCNZ on Facebook for updates on LBC's research, advocacy and awareness work, as well as support opportunities. Or join one of our closed Facebook groups to connect with other patients or support people who understand the challenges of blood cancer.

Support for specific cancers and conditions

@LBClymphoma

@LBCMyeloma

@LBCCChronicLeukaemia

@LBCAcuteLeukaemia

@LBCBloodDisorders

@LBCHaemochromatosis

@LBCMPN

Support for young adults and parents

@LBCYoungAdults

@LBCParentsGroup

Further support pages

@LBCSupportPersonConnect

@LBCBereavement

@LBCCARTTherapy

@LBCNZConnect

(LBC & Health Professionals Connect)



A recent Kids' Club session at LBC's Auckland office



leukaemia &
blood cancer
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Vision to Cure. Mission to Care.

Call us on: 0800 15 10 15

Email: info@leukaemia.org.nz

Visit: www.leukaemia.org.nz

Mail: PO Box 99182, Newmarket, Auckland 1149

LBC has Support Services offices in Auckland, Hamilton, Wellington, Christchurch and Dunedin